

FREQUENTLY ASKED QUESTIONS ABOUT HANSEN'S DISEASE

1. What is Hansen's disease?

Hansen's disease, also known as leprosy, is a complex infectious disease caused by a bacterium. The disease is often mistakenly identified as the "leprosy of the Old Testament," which has been clearly shown not to be Hansen's disease. Hansen's disease is not highly contagious and 95 percent of the human population has a natural immunity. It responds well to treatment and, if diagnosed and treated early, does not cause disability.

The Hansen's disease bacteria infect skin and sometimes other tissues, including the eye, the mucosa of the upper respiratory tract (nose) and the testes. Hansen's disease always involves the peripheral nerves. If untreated, nerve damage can result in crippling of hands and feet and blindness. Early diagnosis and treatment are the keys to preventing Hansen's disease-related disabilities. A person with HD can continue to work and lead an active life.

2. Hansen's disease risk

Those at greatest risk are the family of a person who has the disease, but is not being treated. This could be because they are genetically susceptible and/or because they have prolonged contact with the infected individual. A spouse is the least at-risk family member. At greatest risk are children, brothers or sisters, or parents of an individual with untreated Hansen's disease.

Hansen's disease is not passed on from a mother to her unborn baby during pregnancy. Neither is it transmitted through sexual contact.

3. Is Hansen's disease contagious?

Yes. However, it is not acquired from casual contact such as shaking hands, sitting next to someone on a bus, or sitting together at a meal. Hansen's disease is far less contagious than other infectious diseases. More than 95 percent of the human population has a natural immunity to the disease. Healthcare workers rarely contract Hansen's disease. Most cases of Hansen's disease respond to treatment and become non-infectious within a very short time.

4. Treatment of Hansen's disease

Hansen's disease is curable using antibiotics. The three most commonly used are Dapsone, Rifampin and Clofazimine. Other antibiotics, such as Clarithromycin, Ofloxacin, Levofloxacin and Minocycline also work well against *M. leprae*. Dapsone and other Sulfone drugs were discovered to be effective in treating HD at the National Hansen's Disease Program in 1941. These medications continue to be an important weapon against this disease.

Treatment regimens differ depending upon the form of the disease (see [Treatment Guidelines](#)). The National Hansen's Disease Programs recommends treatment for 1 or two years, depending on the form of disease.

Treatment rapidly renders the disease non-communicable by killing nearly all the bacilli within a few days. These dead bacilli are then cleared from the body slowly, within a variable number of years, so that these dead bacilli may continue to be found in skin biopsies for several years.

The National Hansen's Disease Programs in Baton Rouge, Louisiana, is the only institution in the U.S. exclusively devoted to Hansen's disease. The center functions as a referral and consulting center with related research and training activities. Most patients in the U.S. are treated at National Hansen's Disease Programs Ambulatory Care Clinics in major cities or by private physicians. See more on [National Hansen's Disease Ambulatory Care Clinics](#).

5. Finding Treatment for Hansen's disease

People with Hansen's disease in the U.S. can receive Hansen's disease medications at no cost through their own doctor or through the [National Hansen's Disease Programs Ambulatory Care Clinic](#) closest to them.

For further information, phone the National Hansen's Disease Programs toll-free, weekdays 9 a.m. to 5:30 p.m. at 1-800-642-2477.

6. Where on body is Hansen's disease found?

Because the bacteria that cause Hansen's disease like the cooler parts of the body, the skin and its nerves are affected. This can cause dryness and stiffness of the skin. In some cases affected nerves can swell, causing pain. There can be loss of feeling and weakness in the muscles of the hands or feet.

7. Identifying Hansen's disease

Hansen's disease in the U.S. is rare, but between 150 and 200 new cases are reported each year.

The first signs of Hansen's disease are usually pale or slightly red areas or a rash on the trunk or extremities. Frequently, but not always, there is an associated decrease in light touch sensation in the area of the rash. A loss of feeling in the hands or feet may also be the first signs of Hansen's disease. These changes in sensation are a valuable clue to diagnosis.

Nasal congestion may be a sign of infection, but infection is more often associated with changes of the skin on the face, such as thinning of the eyebrows or eyelashes.

Your doctor can make the diagnosis by doing a test called a skin biopsy, which reveals a particular pathologic pattern and demonstrates the specific "red" staining bacteria. By far the most important diagnostic tool is the biopsy of the rash. There are no reliable 'blood tests' for the diagnosis of Hansen's disease. Although some blood tests are promoted in some countries, they are not used in the United States.

8. Hansen's disease and disfigurement

People with Hansen's disease who are diagnosed and treated early avoid many of the complications associated with the disease and experience no disfigurement or disability. Problems with insensitive fingers or toes can be prevented by avoiding injury and infections to these areas, and by taking the Hansen's disease medicines.

Many patients with the tuberculoid or Paucibacillary form of Hansen's disease can even self-heal without benefit of treatment, but it is the standard of care to treat all patients identified with the disease.

9. Hansen's disease transmission

The most commonly accepted theory is that Hansen's disease is transmitted by way of the respiratory tract, since large numbers of bacteria can be found in the nose of some untreated patients. The degree of susceptibility of the person, the extent of exposure and environmental conditions are among factors probably of great importance in transmission.

10. Exposure to Hansen's disease

If you think you have been exposed to Hansen's disease, you do not need to take any action. Most people have a natural immunity and there is no need for prophylaxis.

We do not yet have a vaccine or a blood or skin test that will tell if you have been exposed or if you have pre-clinical disease, although both of these are active areas of research at the National Hansen's Disease Programs.

Household contacts of people with Hansen's disease should have a thorough physical examination annually for five years. If they develop a questionable skin rash, they should notify their healthcare providers and have the skin rash biopsied to determine whether or not Hansen's disease is present.

11. Hansen's disease in the U.S. and the world

In the U.S., there are approximately 6,500 cases on the National Hansen's Disease Programs Registry. This includes all cases reported since the registry began and who are still living. The number of cases with active disease and requiring drug treatment or management is approximately 3,300.

The NHDP compiles a statistical summary of new cases which present in the United States each year. Between 150 and 200 new U.S. cases are reported to the Registry annually. The largest number of U.S. cases is in California, Florida, Hawaii, Louisiana, New York, Texas and Puerto Rico. ([National Hansen's Disease Programs Data](#))

The World Health Organization, which compiles global Hansen's disease data, registered a total of 296,499 new cases worldwide in 2008. This data indicates a rapid, drastic reduction of the number of cases seen each year for the previous 12 years and have raised questions. See the World Health Organization report, [Global Leprosy Situation 2006](#) (not a U.S. Government Web site, pdf). Such data is very dependent upon operational factors such as the method of case finding (i.e., active screening of high risk groups, vs 'passive' case finding – waiting for patients to come to a clinic).

12. Delayed Hansen's disease diagnosis

Unfortunately, the rash caused by Hansen's disease often resembles other skin diseases. Hansen's disease is a slowly developing, chronic, infectious disease and 2 to 10 years may elapse before clinical signs and symptoms appear.

Moreover most private sector physicians in the U.S. lack experience with this disease, and do not consider a diagnosis of Hansen's disease, even in a patient who has lived in or migrated from a country where Hansen's disease

is prevalent. Often a patient sees several physicians before the correct diagnosis is made, delaying the initiation of treatment even more.

13. Forms of Hansen's disease

Classification of this disease is complex, but overall there are two forms. Tuberculoid (or Paucibacillary – few bacilli) is a limited form of the disease that is contagious. Lepromatous (or Multibacillary – many bacilli) is a more generalized form. Proper classification requires a skin biopsy. These are evaluated at the National Hansen's Disease Programs at no charge.

14. Hansen's disease and tuberculosis

Mycobacterium leprae, the bacillus that causes Hansen's disease is in the same bacterial family as *M. tuberculosis*, the bacillus that causes tuberculosis. Because of this relationship, the National Hansen's Disease Program conducts extramurally-funded research on tuberculosis. For more information, please see the [National Hansen's Disease Program Research](#) Web site.

15. Hansen's disease reaction

Some patients experience what is called a **reaction** after treatment has begun. This is a response of the immune system to dead or dying bacteria and can cause worsening of the rash or a painful neuritis which can affect sensation and/or strength. Reactions are NOT caused by the treatment, and are NOT a sign that the treatment is working.

Reaction can be mild or severe. If mild, no treatment or only over the counter anti-inflammatory medication may be sufficient. More severe reactions can be harmful to nerves and should be promptly treated by a physician. If you think you are having a reaction of any type, it is best to notify your physician so that he can decide on appropriate treatment.